Qualitative Health Research
Volume 18 Number 8
August 2008 1049-1061

10.1177/1049732308320110
http://qhr.sagepub.com
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End-of-Life Care and the Grieving Process: Family Caregivers Who Have Experienced the Loss of a Terminal-Phase Cancer Patient

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Family caregivers of a loved one with advanced cancer are at risk for developing bereavement complications following the loss of the person they cared for. However, little research has studied caregiving and bereavement experiences as an ongoing process. This study was conducted with the aim of identifying the main elements constitutive of the experience of providing care and assistance to a patient with terminal cancer that influence the grieving process. This qualitative study, conducted among 18 family caregivers, led to the specification of six principal dimensions of the caregiving experience: characteristics of the family caregiver and of the patient, symptoms of the illness, the relational context, social and professional support, and circumstances surrounding the death. Among these dimensions, the constituent elements of the caregiving experience that might positively or negatively influence the grieving process were identified. This knowledge is useful for a more perspicuous identification of caregivers who might experience bereavement complications.

Keywords: *caregiving; bereavement; cancer, psychosocial aspects; end-of-life care; palliative care*

Palliative care pertains not only to people facing the end of life, but to their close friends and family as well. According to the World Health Organization (World Health Organization [WHO], 2007), palliative care is defined as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." The World Health Organization (WHO) adds that palliative care "uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated." It thus implies an approach that takes into consideration family caregivers' needs both before and after the patient's death (WHO, 2007).

At this point in time, increasing acknowledgment of the specific needs of family providing end-of-life care to a person with a terminal illness can be observed. However, the exploration of family caregivers' experience in all its complexity reveals the need to acquire a better understanding of their experience when caring for a loved one and its influence on the grieving process. Such knowledge is of crucial importance to help health professionals identify the caregivers at higher risk and to intervene in a preventive way to support them.

Indeed, difficulties experienced within the caregiving context might have consequences on the longer-term psychological health of family caregivers, more specifically during bereavement. According to the literature, a certain proportion of people (10% to 20%) deal with persistent difficulties following the loss of a loved one (Prigerson & Jacobs, 2001). Studies have demonstrated that certain factors are likely to influence bereavement outcomes, including family caregivers' mental and

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Authors' Note: Support for this study was provided by Fonds de recherche en santé du Québec (FRSQ) [Health Research Funds of Quebec]. The authors would like to thank the anonymous reviewers for their very helpful comments and suggestions.

physical health status, perceived social support, symptoms and uncontrollable pain, nature of attachment to the patient, circumstances surrounding the death, and psychological and emotional burden associated with caregiving (Åberg, Sidenvall, Hepworth, O'Reilly, & Lithell, 2004; Bass, Bowman, & Noelker, 1991; Brazil, Bedard, & Willison, 2002; Brown & Stetz, 1999; Cannaerts, Casterlé, & Grypdonck, 2004; Cleiren, 1993; Dumont et al., 2006; Ferrario, Cardillo, Vicario, Balzarini, & Zotti, 2004; Gilbar & Ben-Zur, 2002; Grunfeld et al., 2004; Kierse, 1995; Koop & Strang, 1997, 2003; McHorney & Mor, 1988; Mongeau, Foucault, Ladouceur, & Garon, 2000; Norris & Murrell, 1990; Schulz et al., 2001; Séguin, 1999; Thulesius, Hakansson, & Peterson, 2003). However, these results are not consistent throughout the scientific literature and the variables investigated differ greatly from one study to another. Several of these writings stem from clinical impressions and studies that have not examined family caregivers' experience qualitatively.

To shed light on this issue, in this qualitative study we aim to specifically identify caregiving factors that are likely to influence the grieving process of family caregivers who provided care and assistance to a patient until his or her death.

Conceptual Framework

To date, there is no satisfactory conceptual model that takes into account both the pre- and postdeath experiences. Accordingly, this study is based on three conceptual models selected for their relevance and for their complementary contributions. The first model, that of Dumont et al. (2000), pertains to psychological and emotional burden experienced by family caregivers during palliative care. Additionally, the model proposed by Richard Schulz (1990) on the concept of caregiving, which is more specific to the context of palliative care, as well as that of J. William Worden (2002) on grief determinants, were used to orient comprehension of family caregivers' experience.

Research Question

To meet the study's objectives, the following research question was formulated: From the perspective of bereaved family caregivers, what are the elements of the caregiving experience that significantly influence (positively or negatively) adjustment to bereavement?

Method

Participants

In this study, we focus on the experience of family caregivers who provided care to a terminal-phase cancer patient and, more specifically, on their bereavement experience. To obtain data on this topic, a qualitative study was conducted among 18 family caregivers. Family caregiver is defined here as "those members of a family who fulfill the role of main caregivers of a patient during the palliative phase of patients with cancer" (Dumont et al., 2006).

To be included in the study, the family caregivers had to have (a) acted as primary family caregiver to a patient within the home environment during the terminal phase of cancer; that is, when the patient was partially or completely dependent; (b) provided care and assistance to the patient on a daily basis; and (c) lost the patient 3 to 4 months prior to the interview. People who, from the perspective of the health professional, manifested a level of exhaustion such that participation in the study would likely have had a negative impact on their health were not invited to take part in the study.[1]

Procedure

Participants were recruited as part of a larger longitudinal quantitative study. Sixty three participants were met at baseline while acting as family caregivers of a terminal-phase cancer patient. From this original sample, 35 participants were also met at two follow-up points postdeath (3 to 4 and 7 to 8 months postdeath). Of this cohort of 35 participants, 18 family caregivers participated in the current qualitative study. The process of sampling allowed reaching saturation. Indeed, 18 participants was sufficient to conclude that no new information or new themes were likely to emerge from further data analysis.

Recruitment was conducted upon application for admission by the investigator of the current study in collaboration with liaison nurses and psychosocial clinicians working within a hospital specializing in palliative care. At the end of the first follow-up interview (3 to 4 months postdeath) of the larger quantitative research, family caregivers were told about the current study. Informed consent was obtained from family caregivers who were interested in taking part in this qualitative study. The qualitative data presented here were collected 4 to 5 months following the patient's death. The study was approved by the Research Ethics Committees of Laval University and La Maison Michel-Sarrazin Hospice, located in Quebec, Canada.

Data were gathered between November 2004 and December 2005. The investigator made home visits to complete the informed consent process, answer questions, and administer interviews. The interviews were conducted in French and lasted 50 to 90 minutes. All interviews were recorded and their content transcribed verbatim. An interview grid was developed based on the conceptual framework chosen to guide data collection (see appendix). The first question on the interview grid, being open-ended, enabled the researcher to be guided by the participant's discourse while ensuring that all study aspects were addressed.

The first open-ended question addressed the family caregivers' bereavement experience. Family caregivers were then questioned about the caregiving constituent elements that might have facilitated or hindered the grieving process. They were also asked about themes they did not address spontaneously, but that according to the conceptual framework were to be explored to meet the study's objective.

Data Analysis

Content analysis of the qualitative interviews was conducted by the first author (ID) according to the steps recommended by Bardin (1991): coding, categorization, and creating interrelations leading to a themed description of the study problem. Procedures for monitoring the credibility of the data included peer debriefing and review of the codes by the second (SD) and third (SM) authors, who have expertise in caregiving.[2] Qualitative research software QSR NU*DIST (n.d.) was used to process the data.

Results

Description of Participant Characteristics

Participants' ages at the time of interview ranged from 33 and 75 years; most participants (61%) were women. All of the participants were of Roman Catholic background, with the exception of one caregiver who reported being an atheist. The sample was comprised of 12 family caregivers who provided care to a spouse. The remaining 6 family caregivers cared for a parent or a friend.

Being a caregiver to a person with advanced cancer might be an existentially rich experience, but might also be psychologically and physically demanding, particularly during the final moments of the patient's life. Indeed, for those who reported having adjusted well to bereavement, the caregiving process was perceived, overall, as an opportunity for personal growth and valorization. For others who mentioned having "had a lot of difficulty throughout the grieving process," caring for a loved one with cancer was, on the contrary, felt to be a disruptive experience that had a rather negative influence on their current adjustment to bereavement.

Analysis of the family caregivers' discourse made it possible to identify the principal elements associated with caregiving that might exert an influence on the grieving process. The data presented in the current study illuminate the particular experience of family caregivers who cared for an advanced cancer patient. This experience can be complex because cancer is often associated with intense symptoms that can be difficult to control and that usually make the patient's health unstable (Seale & Kelly, 1997).

According to the comments gathered, the principal dimensions of the caregiving context that most significantly modulate (positively or negatively) family caregivers' experience are (a) characteristics of the family caregiver (attitudes, religious and spiritual beliefs, personal competence, psychological and emotional burden); (b) patient characteristics (attitudes, relation to death); (c) symptoms of the illness (confusion, major behavior changes, cachexia); (d) the relational context (relationship with the patient and other family members); (e) social and professional support; and (f) circumstances surrounding the death (moment of the death, preparedness for death). These dimensions will now be presented in such a way as to highlight their positive and negative impact on family caregivers' bereavement processes.

Characteristics of the family caregiver. According to the analysis of the comments gathered, certain characteristics of the family caregiver are perceived to facilitate adjustment to bereavement. First, the family caregiver's attitude is a key element in the way that grief is experienced. For example, becoming aware of one's own finitude is an attitude (or insight) that was predominantly brought up as having a positive impact on bereavement. Such an awareness led family caregivers to "get closer to life" and to live their lives fully, despite the great sadness associated with the loss of the patient. Indeed, this attitude encourages them to better tackle unavoidable grief work and to reinvest in life with more determination. According to the German philosopher Martin Heidegger (1962), it is recognition and acceptance of the finite nature of human life that provides structure to one's existence and the resolve to commit to meaning-giving projects.

> It's just that we're not much on earth, but we must live out our life. . . . So you have to live your life to the most. 100%. It helps to have energy and to get through moments of sadness.[3]

Moreover, the ability to be optimistic and assertive toward others while respecting one's personal limitations to obtain needed assistance and support, as well as the ability to reorient one's life according to one's own values and personal objectives, are the types of attitudes that are considered to have a positive impact on adjustment to bereavement. Furthermore, the family caregivers mentioned the positive influence of religious and spiritual beliefs on the grieving process. The caregiving context might give rise to metaphysical reflections on the meaning of life and one's rapport with what is sacred and transcendent. Powerlessness felt before the disease leads many to believe in a greater force. A large number of the participants reported that this type of belief helped them to deal with the multiple demands of caregiving and the difficulties inherent to the loss of the patient; however, the fact that all but one of the participants were Roman Catholic should be taken into consideration.[4] Indeed, this result might not be generalizable to caregivers from different religious and spiritual backgrounds.

The testimonies gathered also highlighted the positive influence of past experiences on grief reactions. Indeed, family caregivers pointed out that having lived through adversity in the past provided preparation for the difficulties encountered while caregiving and through bereavement. Small and large past ordeals are retrospectively regarded as occasions for learning and character development:

> I stayed despite his mental disorder. . . . To live with a manic-depressive, you almost have to have the heart of a nun. He also had suicidal ideas. My life with him wasn't easy. So I believe that what I went through [caring for him while he had cancer] prepared me, to some extent, for his death, for this trauma, because I've already experienced other trauma.

The multiple tasks associated with caregiving require offering emotional support, in addition to providing care and responding to the patient's many needs. In this regard, past experiences are perceived by the family caregivers as an important source of the required know-how and for adopting the family caregiver role:

> Having already experienced being a caregiver for my previous husband, I already knew what it was. It helped me. With my husband, I can at least say that I knew how to be a caregiver.

The caregiving context is thus experienced as an occasion to play an important role for the patient and to decrease guilt often inherent to the grieving process. Indeed, guilt is a feeling often present among those left behind. The impression of having "done everything" they could for the loved one is an element that has a major positive impact on grief reactions. Indeed, this impression contributes to providing meaning to the pain and loss felt following the patient's death and greatly decreases guilt during grief:

> I don't regret anything of my experience. I don't have any bad memories. If you ask me, I think I did all that I could for him. I gave him everything that I could. Today, I'm happy that I did.

Moreover, family caregivers who experienced a feeling of competence and who perceived caregiving as an opportunity for personal growth adjusted, in general, more easily to the loss of the loved one.

> It's the most enriching experience of my life. It's an experience I would go through again without any hesitation. It has been so rewarding for me, morally, spiritually, physically, because it helped me understand that I need others to live a good life. I am so proud that I've done it. I believe it gives me a sense of fulfillment despite the sadness of what I am going through now.

These family caregiver characteristics modulated the grieving process in a positive manner. Yet, certain characteristics seem to have a rather negative impact on bereavement. For example, adopting certain types of attitudes, such as denial of the illness and end of life, in addition to aggressiveness, make the caregiving experience more difficult, which in turn has negative repercussions on adjustment to bereavement. Moreover, family caregivers' difficulty expressing feelings, as well as psychological and emotional burden felt throughout the caregiving experience, are aspects that hindered adjustment to bereavement. This situation might have detrimental consequences on the family caregiver's health following the patient's death:

> I know that it's inside of me and it should come out. . . . I'm sad, but I don't cry. It has been a week or two that I have had difficulty sleeping. I start to think about it. It certainly doesn't help me to get

> through the day. Even my boss said that I seem more tired and aggressive at work as well.

Sometimes one's environment is not conducive to the expression of feelings of sadness by the family caregiver. One family caregiver described this situation:

> My sister-in-law came out of the room where I was and she said "Gawd! She's crying right next to him!" I couldn't express myself. I don't even know if I've finished grieving. I still find it difficult.

Furthermore, family caregivers' perception of the multiple demands associated with caring for a patient might have long-term consequences on psychological and physical health, as well as the grieving process. Here, we speak of the notion of psychological and emotional burden that is defined, according to Dumont et al. (2000), as a "psychological and emotional experience related to the perception of the various caregiving demands specifically associated with the act of looking after a loved one at the end of life." For example, as shown in the following excerpt, feeling strained and wondering if one's health will enable one to continue providing care and assistance to the patient until the end are constituent elements of psychological and emotional burden:

> Me, I spent three and a half months with him at home, day and night, giving him morphine. I saw him suffer every day. . . . At some point, I asked myself if I would have the strength to continue. I still think that I'm physically and psychologically worn down, to a certain extent.

Sometimes there are contradictions between the family caregiver's desires and those of the patient. In some cases, responding to the patient's demands increases psychological and emotional burden, in addition to having negative consequences on the family member's experience after the loved one's death:

> He didn't want me to go to bed with him in the evening [at the palliative care center]. But you still feel guilty to have obeyed, even when grieving. I would think to myself—he died a little before his time—if I had known during that week that he would die, I would have stayed every evening and I would have stayed with him all the time.

Patient characteristics. According to the participants, the patient's attitudes toward the illness impact the way family caregivers go through caregiving and grieving. For example, a "serene attitude" as well as acceptance of end of life positively influence family caregivers' grief reactions:

> [There is also] the way in which the person deals with his illness. My husband's attitude. Being serene and not making my life miserable. It helped me a lot. He was always positive. It still helps me when I'm more sad.

According to discourse analysis, family caregivers of patients who adopted an attitude of denial toward end of life had more difficulty recognizing the reality of the death and progressing through the grieving process. As demonstrated by the following excerpt, the patient's denial of the disease also creates a more hostile environment for the expression of feelings of sadness and chagrin by the family caregiver:

> My husband appeared very strong in light of the illness, and he did everything he could for it to be that way. Me, I went through it with a lot of difficulty. A lot. What I found difficult is that he would not let himself see that he was ill. It seemed as though he denied the disease. Me, I would have cried the whole time. Him, no. Now, it seems as though I am not able to see reality face-on and to get through my period of mourning.

In cases where the patient displayed aggressive behaviors, end of life evokes bad memories for the family caregiver and negatively taints bereavement:

> I would tell myself that he is not my father. . . . The guy who came to wash him, my father kicked him. He even told my sister that she was stupid. Therefore, I didn't even want to show my face. Then, the girl came to find me to help put in the IV. I didn't like that at all. I had to hold his arm and he stared at me. I don't know what he was thinking. I was always scared. In the end, he didn't say anything. I think I'm still scarred by that today. Those are moments we never forget.

Symptoms of the illness. Symptom management in the patient also influences adjustment to bereavement. For family caregivers, the loss of the patient is easier when he or she did not suffer and was able to preserve a certain quality of life:

> I thanked God afterwards for having come and taken him away. He didn't suffer. I was alone, but I was happy. I could not have seen him live that way. I would have suffered more than him to see him suffer. It puts me at peace when I think that he at least didn't suffer. It helps to get through grieving.

However, the presence of some symptoms in patients, particularly confusion, major changes in behavior, and the presence of cachexia, was identified as an aspect of caregiving that made the end-of-life experience more difficult for the bereaved family. Indeed, these symptoms can be very destabilizing for family caregivers and might lead them to no longer recognize the person to whom they are devoted. Furthermore, family caregivers' image of the patient who presents these types of symptoms does not usually remain intact, and this new perception might affect reactions to the patients' death. According to the comments gathered, these aspects of caregiving negatively affect reactions to the loss of the patient:

> I think of the image I have of her [my mother]—she would get up during the night; I would see her pass by, shoulders rounded and head lowered. She walked like a little mouse. She went to the bathroom and came back. I think I'll always see her go by that way. It affected me a great deal. The woman who didn't want for us to help her . . . when you end up having to put her in diapers. My God . . .

The relational context. Unsurprisingly, the quality of the relational context within which the family caregivers function is a caregiving aspect that impacts their perception of their experience. The family caregivers commented, among other things, on the fact that preserving usual benchmarks and communication with the patient positively oriented their grief. Indeed, this was a way for the family caregivers to get in closer touch with life and to enjoy the other's presence despite the disease. Moreover, family caregivers' testimony reveals that good communication with the patient and a mutual acceptance of the illness help the family to progress through caregiving and bereavement with more serenity:

> What helped me a lot was that while being a caregiver, we carried out our normal life together. He watched a lot of television. We watched that together like we did before. I'm happy to have done that until the end. It was as though we both enjoyed life together until the end. I still have beautiful memories.

The relational context can thus be conducive for an existentially rich experience and reinforces existing ties between the family caregiver, the patient, and the family. However, the comments gathered indicated that certain situations, such as a dependent or ambivalent relationship between the family caregiver and the patient, as well as the presence of family conflicts, might hinder progress throughout the different stages of grief. For the family caregivers, this type of situation leads to feelings of abandonment, insecurity, anger, or even loss-related guilt:

> I felt safe with him because each time that I asked him a question, he had the right answer. Now, what I feel the most is insecurity. . . . At first I panicked. I asked myself if I would be capable. When you relied upon your husband all your life. Me, I gave him my paychecks. He gave me as much money as I wanted. It is not easy to live without him.

The presence of tensions is, in many cases, attributable to differences in opinion between family members. If these differences are too great, a schism might develop between these family members and the family caregiver. This situation might have a negative influence on family caregivers' experiences before and after the patient's death:

> I felt tugged in several directions. Me, I wanted to respect everyone. Each had their way of seeing things. At some point, it became too much. It is now difficult to forget all that and to move on. Actually, I have to say that I went to see my psychologist.

The discourse of the family caregivers interviewed also underscored the importance of receiving recognition for their role from other family members and loved ones. In some family caregivers, the absence of this recognition might give rise to feelings of anger, bitterness, and abandonment, which in turn impacts their bereavement experience:

> I did what his family should have done instead of me, but instead they said, "thank you, you have been kind," but nothing more than that. No acknowledgement. I am not a scumbag. You feel all alone. I even thought I would have to consult. I feel suffocated. I feel all alone, forgotten.

Social and professional support. Participants' comments shed light on the importance of support and assistance from family, friends, and health professionals. Satisfactory social and professional support is an aspect of caregiving that can decrease anxiety and distress in family caregivers and positively orient their bereavement. Moreover, several family caregivers expressed difficulty asking for help from those around them. For example, a family caregiver mentioned the importance of being able to benefit from "proactive assistance" to meet her needs:

> Me, it is help that I call proactive that I found the most helpful. For example, my sister called me one morning and said that she would take my son to hockey. I didn't have to ask her. It is still like that since the death of my spouse. It's good for morale.

As for professional support, analysis of the family caregivers' comments indicates that satisfactory support is of primary importance during both the caregiving and the grieving processes. Indeed, clinicians offered security, a listening ear, information, and support essential to moving through the stages of the patient's end of life, which had positive repercussions on adjustment to bereavement.

Circumstances surrounding the death. The event of death is itself a traumatic moment for the person who cares for the patient. However, as one family caregiver mentioned, the circumstances surrounding the death can "lessen the pain related to the loss" and even be "a beautiful moment" for the loved one who is with the patient at their death, and who stayed by his or her side until the end.

Circumstances surrounding the death that help family caregivers to move through the mourning process included (a) being present at the time of death, (b) a "beautiful death," (c) respect for the sacred nature of death and the patient's dignity, (d) preparedness for the death (grieving before the death), and (e) postmortem organization.

Being present at the time of death decreases feelings of guilt inherent to the grieving process and seems to reduce the degree of distress experienced by the bereaved person. The comments gathered reveal the great importance of accompanying the patient until the end and of being present for the patient's "last breath":

> I'm happy it happened the way he wanted it to and to have been there. I am happy that he died in my arms. I was able to be with him until the end.

Moreover, the moment of death is the end of a caregiving process, which is an emotionally charged event. According to the family caregivers, a "beautiful death," meaning a peaceful and serene death, as well as the fact that the patient was able to die within a setting that respects what some see as the sacred nature of death (as being part of life), as well as the patient's dignity, positively influence reactions to the loss. In reality, memories of the final moments orient the person's progress throughout the grieving process. In this sense, a family caregiver described the death of her mother by saying,

> I have a positive memory of when she died. We went outside and the sun was rising, it was so beautiful. For sure, I felt sad, but my boyfriend was there and it was very tender. But the moment the sun rose in the distance, it was really beautiful. It was orange. She died at 5:20, so it must have been 5:45 afterwards. That's what I said to my spouse—the last image I want to keep is that one.

Preparation for the loss is another aspect of end-of-life care that facilitates the grieving process. Usually, grieving begins at the moment when loss is perceived to be inevitable (Hétu, 1998). Experiencing different losses associated with death while providing care to the patient is one way to begin grief work before death takes place. Indeed, caregiving might provide an opportunity to prepare oneself, to some extent, for the ultimate loss and to begin personal growth that continues after the loss:

> The last night that we slept here, it had been 41 years that we slept together. So, at one point, near four o'clock in the morning, we both got up and cried together. We said to each other that it really is the last time that we'll sleep together. We realized it together and everything. It was not easy at the time, but it helped me later.

The patient's death is an event that might also lead the bereaved to experience insecurity. Taking on certain practical tasks such as paying bills or tax declarations increases stress and anxiety during bereavement for family caregivers who did not usually do these tasks. The advice and assistance received by the patient or loved ones before death contribute to decreasing anxiety and facilitate the grieving process:

> My husband said that he would take care of me because he knew that I would be tired. He gave me a lot of advice. . . . Before he died, he showed me all of the practical business because it was him who took care of all that. . . . We even went together to make his funeral arrangements before he died. That was helpful for me; now I feel less worried.

The patient's death might be perceived differently depending on the circumstances in which he or she lived. Certain circumstances surrounding the death might have negative repercussions on reactions following the loss. These circumstances relate to the patient's departure from the home to a palliative care hospice or hospital and the particular moment of death.

Family caregivers who participated in the study had all cared for a patient at home. However, for some of them, the patient ended his or her days in a palliative care hospice or a hospital. For most of these family caregivers, the moment of the patient's departure was experienced as a key step in end-of-life care, and as the most difficult moment. This difficulty is explained by the fact that the patient's departure confronts the family caregivers with the implacable reality of the eventual loss:

> The hardest part was when she left the home. Out of all that happened, that is what struck me most. It's difficult when you say to yourself that it is the last time she will go out. I still think about it. Her death was so peaceful. You hardly knew it. But here, it was more difficult. It was a rattling event that I'll never forget.

The actual moment of death can also be very difficult for people who provide care to the patient. Indeed, family caregivers reported having found it very trying to see the patient die, particularly for those who did not feel prepared. The images associated with these final moments might then become recurrent throughout the grieving process and negatively modulate adjustment to bereavement:

> The time of her death was difficult for me to experience. First, I had never seen a person die, I wasn't prepared for that. When she took her final breath, she kind of lifted herself up from her bed and she opened her glazed-over eyes—the eyes of death. I will never forget that look! Sometimes, these images come back to me and I don't find it easy.

Discussion and Recommendations

In this study, we aimed to identify, through interviews with family caregivers, the principal dimensions associated with the caregiving experience that significantly influenced (positively or negatively) their bereavement. Analysis of the comments gathered led to the identification of six principal dimensions: characteristics of the family caregiver (attitudes, religious and spiritual beliefs, personal competence, psychological and emotional burden), patient characteristics (attitudes, rapport with death), symptoms of the illness (confusion, major behavior changes, cachexia), relational context (relationship with the patient and the other family members), social and professional support, and circumstances surrounding the death (moment of death, preparedness for the death). For some family caregivers, caregiving was an opportunity for personal growth and valorization. Yet for others, caregiving was experienced as disruptive and as having exerted a rather negative influence on the grieving process. A synthesis of the principal elements that were identified through interviews with family caregivers is presented below.

Detrimental elements
- Difficulty expressing one's feelings
- Presence of psychological and emotional burden
- Patient's denial of the disease, or aggressiveness
- Presence of symptoms in the patient such as confusion, major behavior changes, and cachexia
- Uncontrollable pain
- Communication problems between the patient and the family caregiver
- Ambivalent or dependent relationship with the patient
- Presence of family tensions
- Unsatisfactory informal (family and friends) and formal (care personnel) support
- Patient's departure to a hospital or a palliative care home
- The moment of death (graphic images of the death postbereavement)

Facilitating elements
- The family caregivers' attitudes (e.g., optimism, ability to be assertive), religious and spiritual beliefs, and previous experiences
- The patient's attitudes (acceptance of the illness)
- Control over pain and suffering
- Presence of significant relationships between the family caregiver, the patient, his or her family, and friends
- Satisfactory informal (family and friends) and formal (care personnel) support
- Family caregiver's presence at the time of death
- Respect for the sacred nature of death and the patient's dignity
- Preparedness for the loss
- Postdeath organization

Caregiving elements likely to influence the grieving process. Certain findings of this study coincide with those of some of the few already-existing written works on the topic and with the conceptual framework adopted by this study. For example, Koop and Strang (2003) carried out a qualitative study among 15 bereaved people who had provided care and assistance to a patient with advanced cancer to explore the consequences of home care on bereavement. Like in this study, they demonstrated that the impression of having given one's all to the patient had the effect of decreasing feelings of guilt, which are often experienced following the loss, and consequently had a positive influence on grief reactions.

According to a study by McHorney and Mor (1988), people who express dissatisfaction regarding their personal competence as a family caregiver are twice as likely to experience a postdeath depression. This result concurs with this study's finding that the development of feelings of competence facilitates the grieving process among family caregivers.

The comments gathered also reveal the impact of the patient's attitudes on the family caregiver's grief following the loss of the patient. For example, denial of the disease and end of life makes the caregiving experience more difficult and has negative repercussions on the grieving process. In fact, the need of family caregivers for the patient to become fully aware of the imminence of death has been underscored by several authors.

Moreover, like in the studies conducted by Mongeau et al. (2000), as well as Koop and Strang (2003), this study supports the theory that uncontrollable pain and symptoms are aspects of caregiving that make the grief experience more difficult for bereaved family and friends. The research participants also revealed, as did Gilbar and Ben-Zur's (2002) study, that memories of the disease's devastation of the loved one might also negatively impact the grieving process.

With regard to the participants' characteristics, religious and spiritual belief was mentioned as a facilitating disposition likely to influence the grieving process. Nevertheless, all family caregivers but one who participated in this qualitative study were Roman Catholic. The homogeneity of religious and spiritual beliefs is a limitation of the study and might have impacted its findings. Indeed, it would have been interesting to hear about how different religious and spiritual beliefs and different ways of relating to one's religious background could influence the bereavement experience. Moreover, given that all the participants were White, the sample was fairly homogeneous along the standard social category of ethnicity. However, both men and women caregivers with a wide range of ages (33 to 75) were represented in the study.

As pointed out, the relational context is a dimension of the palliative care phase that influences bereavement. For example, the comments gathered within the scope of this study indicate that the presence of family conflicts might lead family caregivers to have more difficulty dealing with grief reactions following the loss. In this regard, Gilbar and Dagan (1995) reported in their study that the risk of experiencing a postdeath depression among family caregivers who were faced with family tensions were 1.4 times greater than among those whose family relationships were more harmonious.

As for the family caregiver's relationship with the patient, the influence of these ties in relation to bereavement has been well documented. Several authors agree that the intensity of grief is, in most cases, proportional to the strength of the emotional relationship and depends on the significance of the deceased person in the eyes of his or her family and friends (Bacqué, 2000; Bacqué & Hanus, 2001; Bernard & Lavoie, 2004; Bourgeois, 1996; Fergus, Gray, Fitch, Labrecque, & Phillips, 2002; Hétu, 1998). This relationship was indeed expressed by the participants of this study. However, it should be pointed out that certain aspects of caregiving, such as the patient's serene attitude, the family caregiver's impression of having given one's all, the development of feelings of competence, and the presence of satisfying social support might protect the family caregivers from complicated grief, even if the ties to the caregiver were very strong. Consistent with this observation, the results of a qualitative study by Sinding (2003) suggest that the value assigned to closeness with the ill person can be seen to reflect a cultural expectation of what is considered as a "good death," and to shape family caregivers' perceptions of their role. Yet, in cases of an ambivalent or dependent relationship, long-term difficulties experienced following the loss are even more probable. Such relationships often engender profound guilt and might be accompanied by aggressiveness by the bereaved person, who considers him or herself to be "abandoned."

Moreover, the study's findings, as well as the conceptual models of Schulz (1990) and Worden (2002), which all highlight the protective effect of social support against the development of health problems (psychological or physical) related to trying events such as the loss of a loved one, are acknowledged by several authors.

Finally, according to the remarks gathered, circumstances surrounding the death, such as being fully aware of the numerous and successive losses associated with end of life (for example, becoming aware of the fact that it is one's last meal with the patient, that the patient will no longer walk or participate in the same activities as before, etc.) is another aspect of palliative care that appears to facilitate the grieving process. Similarly, Koop and Strang (2003) also shed light on the benefits of acknowledging losses inherent to the death, as well as beginning grief work, in some manner, on the personal progress of family caregivers.

The purpose of this study was to identify, in a specific manner, the elements constitutive of caregiving that are likely to influence the grieving process. In this sense, it provides a fuller comprehension of family caregivers' experiences before and after the loss. Indeed, it considers palliative care and bereavement as part of the same existential experience—which few authors have done—despite concerns manifested by clinicians who specialize in this field.

One significant point that can be learned from this study is that, according to the comments gathered, the moment death occurs is a pivotal moment that might have major consequences on family caregivers' grief reactions. For example, many of the family caregivers questioned underscored the importance they attributed to the patient having a "beautiful death," meaning a death that can be described as peaceful and serene, and the positive influence it has on the grieving process. Yet, some accounts illustrate that the particular moment of death is difficult for people who provide care for the patient, particularly for those who feel they are not prepared. The images associated with these final moments might negatively affect the bereavement experience.

Quality end-of-life care will not necessarily enable the patient to face the violence of death with a certain level of acceptance and serenity. Indeed, the reality often is that, despite family caregivers' good intentions, presence, compassion, and a listening ear, the patient might still face the end of life in denial and with anger. In such cases, family caregivers often express distress and difficulties grieving. Support offered to family caregivers to assist them in facing end of life and attaining realistic expectations toward the patient's death, and the role they might play for this patient, is necessary to facilitate the grieving process and therefore the prevention of bereavement complications.

Family caregiving is an important aspect of palliative care. The findings of this study shed light on the positive influence of support that adequately responds to the needs of family caregivers before and after the loss. For this reason, it must be reasserted that support programs for family caregivers must be considered, in palliative care settings, as an essential service that contributes to lessening the negative physical, psychological, and social effects related not only to caregiving, but following the loss. Accordingly, support programs for family caregivers must be seen as belonging to a preventive care strategy aiming to decrease distress during the caregiving period, as well as following the patient's death.

To offer support adapted to the needs of family caregivers, it is important to appropriately target the dimensions on which to intervene, from the beginning of caregiving to the grieving process. Such interventions should thus take into account the six principal dimensions influencing family caregivers' experiences that were identified here. Of these dimensions, circumstances surrounding the death—more particularly the moment of the patient's death—is a step that is often very emotionally charged. The comments gathered within the scope of this study revealed that support for family caregivers that enables them to speak about this end-of-life step is an important element in the implementation of interventions aiming to decrease the risks of difficulty adjusting to bereavement.

Relational context was also a key element for several participants. Indeed, among the family caregivers who had the most difficulty dealing with their pre- and postdeath experiences, a large number expressed having to cope with a relational context that was not favorable (presence of family tensions, poor communication, lack of acknowledgment of the caregivers' role). This result could be explained by the fact that this aspect affects family caregivers on several levels: their relationship with the patient and with other family members, as well as, on an individual basis, the development of a feeling of personal competence. These results suggest that a family approach targeting all the family members of the patient might have a positive effect on their functioning and help them to adapt to the different stages of illness and bereavement. Family interventions have already proved themselves in several fields, including palliative care. In fact, it has been demonstrated that this type of intervention might decrease the risk of experiencing distress or comorbid complications throughout the caregiving and grieving experience among family caregivers (Kissane & Bloch, 2002). Moreover, preventive intervention offered at the beginning of caregiving, followed by a postdeath section providing continuous support for grieving family caregivers would favor the continuity of support for family caregivers and reduce the risk of developing bereavement complications.

Conclusion

Very few studies have explored family caregivers' experience before and after the loss of a person with a life-threatening illness as elements of a single process. The objective of this study was to fill this gap by acquiring knowledge regarding dimensions of the caregiving experience that influence family caregivers' bereavement.

Let us bear in mind that without the devoted assistance and support of family caregivers, home care would not exist and that this form of care now constitutes an indispensable part of several overall care systems. We now know that the health status of family caregivers is at risk for degrading during the caregiving phase. Indeed, according to the results of a study conducted among family caregivers of patients in an advanced phase of cancer, nearly 70% were experiencing a high level of distress once the end-of-life patient presented a large loss of autonomy (Dumont et al., 2006). It is thus imperative to develop more knowledge and to put resources into place that would better respond to the needs of these family caregivers. In our study we demonstrate that, in addition to the psychological distress experienced during palliative care, certain family caregivers will suffer chronic distress and depression for months following the patient's death. Other studies are necessary to learn of the relative importance of the dimensions identified by this study and to more specifically evaluate the short-, medium-, and long-term effects of the caregiving experience on the quality of life of those who are bereaved and who provided care for the patient. Until then, it is important to acknowledge the essential contribution of family caregivers and therefore encourage the development and continuity of institutional and social support initiatives that are better adapted to their needs.

Appendix
Semistructured Interview Grid

Open-ended question to initiate the research interview with family regarding their grief experience:

How would you describe your bereavement experience since the loss of the loved one for whom you provided care during his or her disease?

The following questions made it possible to address the themes not covered by the family caregiver and that are linked to the conceptual models used within the scope of the study.

Theme 1: Nature of the Attachment
- Tell me about the relationship you had with the person you cared for.
- Intensity
- Attachment security
- Dependence
- Ambivalence
- What changes are you now experiencing in his or her absence?
- Financial aspects
- Daily tasks
- Presence of anger and/or guilt

Theme 2: Circumstances Surrounding the Death
- What were the final moments like for you?
- Patient's state during his or her final moments of life
- Accrued presence of symptoms
- Pain relief
- Location where the death took place
- Duration of the illness
- Preparation for bereavement
- Expression of feelings
- Tell me about what you experienced after his or her death.
- Reactions to the death
- Medical procedures
- Funeral
- Burial
- Succession

Theme 3: Antecedents
- Let's go back to your caregiving experience. What was it like acting as a family caregiver?
- Caregiving context
- Participation in the care
- Feelings of competence
- Burden felt
- Have you experienced losses other than that of the person you provided care for?

Theme 4: Personal Data of the Bereaved Person
- How do you perceive your health status? Have you noticed changes in your physical health or in your mood?
- We spoke of your caregiving experience and the loss of your loved one. Tell me about your reactions to his or her death.

Theme 5: Social Data
- During your caregiving experience, and now during your period of mourning, what do you think helped you?
- Religious/spiritual beliefs
- Participation in rituals
- Did you feel you had satisfactory social support?
- Professional guidance
- Family dynamics
- Informal support

Theme 6: Concurrent Stress Factors
- Over the past months, have you experienced major life changes, such as a birth, a move, or an occupational change?

In Sum
- What are the elements that, from your viewpoint, helped you to go through the caregiving experience and mourning process?
- What are the elements that, for you, made it more difficult to get through your caregiving experience and mourning process?

Notes

1. For more details regarding this study, see Dumont, Dumont, and Gagnon, manuscript in preparation.

2. The current research was conducted as a part of the first author's PhD study under the supervision of the second (PhD supervisor) and third (committee member) authors.

3. This excerpt and the ones that follow are loose translations of the French text (the interviews were conducted in French).

4. It is worth noting here that Quebec society went through a rapid and fairly radical process of secularization in the past 50 years. Many Quebeckers are culturally Catholic but either atheist/agnostic or virtually nonpracticing. A deeper analysis of the role of religious beliefs would have required much more detailed and focused questioning during the interviews.

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